

Treatment Options for Today and Tomorrow



**LIVING BEYOND
BREAST CANCER™**

With you, for you.



Dear Friend:

A diagnosis of metastatic breast cancer can feel devastating, but thanks to scientific advances, people with advanced disease are living longer than ever. Whatever your situation, there are treatments that can help you lengthen and maintain your quality of life.

Still, it is common, and understandable, to feel overwhelmed, scared, sad or angry at the thought of continuous treatment for the rest of your life. Gaining a basic understanding of the disease and treatment options can help give you a feeling of control and a renewed sense of hope. This guide focuses on treatment options and will help you communicate with your doctor. Always talk with your doctor about what you read here or elsewhere.

Everyone deals with metastatic breast cancer in their own way. Many people want to talk to someone going through it. When you are ready, we encourage you to contact our **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** or via online chat at **lbbc.org/helpline** for guidance, information and peer support. Our trained volunteers, who include women with metastatic breast cancer, are here to listen.

We hope the information in this guide will bring you comfort and help you make informed decisions about your health. Remember, you are not in this alone — Living Beyond Breast Cancer is here to help you live as well as possible.

Warmly,

Jean A. Sachs, MSS, MLSP
Chief Executive Officer

Fill out our online survey
today for a chance to

win a \$25 gift card!

VISIT: surveymonkey.com/r/2016LBBC



Tell us what you think of
*Metastatic Breast Cancer
Series: Treatment Options for
Today and Tomorrow.*

Thank you

for helping Living Beyond
Breast Cancer improve our
programs and services.



LIVING BEYOND BREAST CANCER™

With you, for you.

Toll-Free Breast Cancer Helpline
(888) 753-LBBC (5222)
lbbsc.org/helpline

All people pictured in this guide are
LBBC volunteers whose lives have been
affected by metastatic breast cancer.
We thank them for sharing their experiences.

SECTION 1

What You Need to Know to Discuss Treatment Options	4
Goals of Your Treatment	6

SECTION 2

Clinical Trials and You	8
The Phases of Clinical Trials	10
Trial Design	11
Eligibility for Clinical Trials	12

SECTION 3

Treatment Options Available Now	14
Questions to Ask About Treatment	15
Hormonal Therapy	17
Targeted Therapy	18
Chemotherapy	18
Radiation Therapy	20
Surgery	21
Your Treatment Options as a Young Woman	22
Choosing Your Treatment	24
Paying for Treatment	25

SECTION 4

Treatments in the Pipeline	26
Keeping Up to Date	27

SECTION 5

What Happens Once Treatment Begins	28
Managing Ongoing Treatment	32
Moving Forward With Your Life	35

SECTION 6

About Specific Treatments	38
Common Hormonal Therapies	39
Common Targeted Therapies	42
Common Chemotherapy Treatments	45
Other Chemotherapy Medicines	46

SECTION 7

Resources	50
Organizations That Can Help	51
Words to Know	54

What You Need to Know to Discuss Treatment Options

The difference between metastatic and early-stage breast cancer relates to how much the cancer has spread.

Doctors use staging to help plan your treatment and predict your long-term outcome. **Early-stage breast cancer** (stage 0 through stage II) is contained within the breast or nearby lymph nodes. In **locally advanced breast cancer** (stage III), the cancer may have traveled locally from the breast to nearby tissue such as the skin or chest wall but is not in distant sites.

Metastatic (stage IV) breast cancer means the breast cancer cells have traveled from the breast and nearby lymph nodes to tissues or organs far away from the breast, such as the bones, lungs, liver or brain, where they formed tumors that tests or physical exams can find.

If you had breast cancer before, past tests may have shown that treatment got rid of all the cancer. But very tiny cells from the original cancer, cells that the tests could not see, stayed in your body despite earlier treatments. These cells made their way from the breast to other organs of the body.

The cancer cells may not be in your breast now, but when cancer spreads to another body part from your breast, it is still called breast cancer. Under a microscope, the breast cancer you have now will look similar to the original breast cancer and will respond to breast cancer treatments.

In many cases, your doctor will take a **biopsy** (a sample of tissue) and compare it to the initial breast cancer to confirm that the cancers are the same and to find out if some markers (such as hormone receptor or HER2) have changed. These tests ensure that you get the most appropriate treatment. Ask your doctor about the hormone receptor and HER2 status of the cancer and how they affect your treatment choices.

Goals of Your Treatment

Treatment for metastatic breast cancer has two goals. The first is to keep the cancer under control for as long as possible. Doctors believe treatments cannot cure or get rid of the cancer forever. In some cases, though, the cancer can be controlled so it has very little impact on your life for long periods. Depending on the cancer's location and aggressiveness, you may be able to live well for years after your diagnosis.

If a treatment stops working or causes side effects that are too severe, your doctor will talk with you about switching to another treatment. At any time, your doctor may tell you about a clinical trial of a promising new treatment if the treatment under study may be of value to you. (Read more about clinical trials on page 8.)

A second, equally important treatment goal is to maintain your quality of life. Every person responds differently to different medicines, so a treatment that causes few or no side effects in some may cause serious side effects for you. And just because a treatment causes more side effects does not mean it works better — sometimes treatments with few side effects control the cancer just as well.

Throughout treatment, it is important for you to be open and honest with yourself and your doctor about what makes life meaningful for you. It could be going

for walks, traveling, working, actively caring for your children or playing a musical instrument. If you have concerns about how a treatment could impact your day-to-day activities, or if the side effects interfere too much with your everyday life, tell your healthcare team. Your doctor may be able to prescribe a medicine to relieve the side effects or may switch you to another form of treatment. Remember, your needs and goals are the most important part of your treatment plan.

We know living with metastatic breast cancer is not just about understanding treatment options; it's about learning to live with a new way of life. For support, contact our **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** or via online chat at lbbc.org/helpline to speak with a woman who understands.



Clinical Trials and You

A **clinical trial** is a research study that tests how well new medical approaches work in people. It is an important step in the long and careful process of using science to develop better treatment options.

Taking part in a clinical trial may benefit you by offering access to new treatments that are not otherwise available but that may prove to work better than standard treatments. Participating may also assist those diagnosed in the future by helping researchers develop better treatments. All of today's standard breast cancer treatments were found to work in past clinical trials.

Clinical trials are open to people with all stages of breast cancer. They may sound scary, but laws and regulations protect you from harm. Your doctor will only recommend studies that make sense for you. If you enroll, you will get the highest standard of care and regular monitoring by experts. Clinical trials follow strict guidelines that outline who can take part and what treatments are given. The research team must explain the purpose, risks and benefits of the trial to you before you consent to take part.

Federal rules require all clinical trials to go through an **Institutional Review Board**, a committee made up of doctors, nurses and lay people who review and approve studies involving humans. The board must include at least one member from outside the institution running the trial. The board monitors the progress of the trial from beginning to end to ensure that the study is safe for all participants.

Clinical trials may cover some or all of the costs of treatment, and most private insurance plans must pay for routine care expenses associated with clinical trials. Talk with your healthcare team to learn more about expenses you may have when participating in a clinical trial.

The Phases of Clinical Trials

For a therapy to become standard treatment, it must go through three or four **phases** (steps), each with a different goal.

● **Phase I** trials test new treatments in humans for the first time. The purpose is to make sure a treatment is safe. Researchers aim to find a safe dose, decide how the treatment should be given and see how the new treatment affects the human body. Usually fewer than 50 people participate.

● **Phase II** trials continue to test the safety of the treatment and begin to decide if it has an effect on the cancer. Researchers start to study side effects. Phase II trials may involve fewer than 50 to up to several hundred people.

● **Phase III** trials are longer-term research studies involving treatments that have shown promise in earlier phases. The purpose is to compare the new treatment (or new use of an existing treatment) to the current standard treatment. Phase III trials can involve hundreds or even thousands of people.

● **Phase IV** trials are sometimes done after the new treatment has been approved by the U.S. Food and Drug Administration (FDA). These trials gather more information about the risks, benefits and side effects of a new treatment and continue to evaluate how well it works. Phase IV trials can involve several hundred to several thousand people.

Trial Design

In a **randomized** clinical trial (phase III trials and, sometimes, phase II), a computer assigns participants by chance to separate study groups to compare different treatments. Randomized clinical trials are considered the most reliable form of scientific evidence because assigning people by chance ensures the groups will be similar. Also, it prevents choosing treatments because of beliefs about their effectiveness and ensures therapies can be compared objectively.

A randomized trial may be **blinded**. If you do not know what treatment you are receiving but your doctor knows, the trial is **single-blinded**. If neither you nor your doctor knows what treatment you are getting, the trial is **double-blinded**. Blinding ensures you and your doctor's expectations about the treatment do not influence the study results. In a blinded study, you will not know which group you are in.

Other clinical trials are **non-blinded**, and both you and your doctor will know what treatment you are receiving. Non-blinded studies are also known as **open-label studies**.

You will always be told if the study uses a **placebo** (an inactive substance) instead of or in addition to active treatment. Most studies for metastatic breast cancer do not use a placebo alone but may combine it with a standard therapy.

Taking part in a clinical trial is a personal decision. You should gather as much information as possible and weigh the benefits, risks and side effects before deciding whether a clinical trial is right for you.

LEARN MORE

For more information, visit LBBC.ORG and read our *Guide to Understanding Clinical Trials*.

Eligibility for Clinical Trials

To be eligible for a clinical trial, the cancer you have must have the specific traits that match those outlined in the trial. Your healthcare team will recommend clinical studies appropriate for your diagnosis, or you can talk with them about studies that you learned about through your own research. If you have medical conditions that might be worsened by treatment, you may not be allowed into the study.

If you are not eligible to get an investigational treatment through a clinical trial, you may be able to get it through a **compassionate use trial** (also called an **expanded access trial**). Although rare, compassionate use trials give access to medicines already shown to be active and very close to FDA approval.

For more tips on finding clinical trials, read “Treatments in the Pipeline” on page 26.



Treatment Options Available Now

There are many treatment options for metastatic breast cancer, and new ones regularly become available through published research studies and new clinical trials.

With metastatic breast cancer, you may receive one type of therapy or a combination of therapies. Available treatments may include surgery, chemotherapy, hormonal therapy, targeted therapy and radiation therapy.

Because each breast cancer is unique, your treatment may be different from someone else's treatment. This does not mean you are not getting the most appropriate treatment for you.

LEARN MORE

For more information about side effects of treatments, visit LBBC.ORG and read *Metastatic Breast Cancer Series: Symptoms and Treatment Side Effects*.

Questions to Ask About Treatment

Since you may have many options, your doctor will recommend treatment by looking at the nature of the cancer, how the cancer responded to past treatments, the length of time between your first diagnosis and the metastasis, your overall health, your lifestyle and possible side effects. If you are unsure or feel you aren't getting the information you need, don't hesitate to get a second opinion.

QUESTIONS TO ASK BEFORE STARTING TREATMENT

- 1 What is the goal of this treatment?
- 2 Who will be in charge of my treatment?
- 3 How long will the treatment last?
- 4 Do I need to bring someone with me when I get treatments?
- 5 How will I know if the treatment is working?
- 6 What blood tests, scans or other tests will you use to monitor the effectiveness of treatment?
- 7 On average, how long does this treatment usually work?
- 8 What happens when this treatment stops working?
- 9 When should I switch to a new treatment?
- 10 What are the side effects of this treatment?
- 11 Will I feel pain or sickness while I take this treatment?
- 12 What problems should I report to you?
- 13 What can I do to help make this treatment less difficult (dietary choices, support groups, vitamins/herbs, exercise, etc.)?
- 14 How will this treatment affect my lifestyle (family, work, leisure, sexual intimacy, etc.)?
- 15 What other medicines will you give me during treatment to enhance my quality of life?

- 16 What other treatments are available to me now?
- 17 Why do you believe this is the best option?
- 18 What can I expect to happen if I choose not to have this treatment?

Hormonal Therapy

Hormonal therapies are targeted treatments that work to slow or stop the growth of **hormone receptor-positive breast cancer** cells, which grow in the presence of the hormones estrogen or progesterone. They are a form of **systemic therapy**, meaning they can kill cancer cells throughout the whole body. In hormone-positive breast cancers, hormonal therapy can work as well as or even better than chemotherapy.

If you had early-stage hormone receptor-positive breast cancer, it is likely the metastasis will be hormone-sensitive as well. Your medical oncologist may take a biopsy if the original cancer was not tested for hormone receptors or to check to make sure the hormone receptor status did not change from the original tumor.

There are several types of hormonal therapy, and you may be switched from one to another over time if one medicine stops working against the cancer. You may also be given other anticancer therapies at the same time as hormonal therapy. Talk to your doctor about the risks, benefits and side effects of each medicine. (Read more about common hormonal therapies on page 39.)

Targeted Therapy

Targeted therapy is a systemic therapy that is used when a specific feature or marker is present on or within a cancer cell. Only cancers with that feature or marker are expected to respond to the therapy.

If you have breast cancer that is **HER2-positive**, meaning it grows because of too many human epidermal growth factor receptor 2 proteins on breast cells, your doctor may recommend a targeted therapy. Targeted therapies also may be used with hormonal therapy to make that treatment more effective.

Targeted therapies are helping scientists and doctors personalize treatment plans so that they work better at killing individual types of cancer. (Read more about “Common Targeted Therapies” on page 42.)

Chemotherapy

Chemotherapy is a systemic therapy that kills rapidly dividing cells, including those found in some breast cancers. The goal of chemotherapy is to slow or stop the growth of cancer cells to lengthen and maintain the quality of your life.

Whether you get chemotherapy depends on many factors, such as:

- the type of cells in the breast cancer
- your age and whether you have gone through menopause
- the presence or absence of estrogen and progesterone receptors
- the amount of HER2 protein on the surface of the cancer cells
- what treatments you received in the past
- how much cancer is in your organs

Chemotherapy can be put directly into your blood. Sometimes it is taken by mouth (**orally**) in pills or capsules, but usually it is given **intravenously** (through a vein). Your healthcare team may recommend a device called a **port** to make delivering chemotherapy safer and easier. The port is placed under your skin in the upper part of your chest and connects to a major vein. It lets you avoid repeated needlesticks in the arm and lowers the risk of certain chemotherapy-related side effects. Another option is a **PICC line**, or peripherally inserted central catheter, a long, flexible tube inserted into a vein in the arm that gives access to larger veins.

Chemotherapy medicines may be given alone (**single-agent therapy**) or together (**combination therapy**). They can be used with other types of treatments. There are many different kinds of chemotherapy, and your doctor will decide the best treatment for you based on the traits of the cancer and your treatment goals. Your doctor also will decide how much chemotherapy you receive and how often you get it. (Read more about “Common Chemotherapy Treatments” on page 45.)

Chemotherapy causes side effects because it kills all quickly dividing cells — including those that affect hair and nail growth and those in your bone marrow and digestive system. Each medicine has a different set of side effects. These may include hair loss, nausea, vomiting, diarrhea, weight gain or loss, fatigue, insomnia, dry mouth, dry skin, mouth sores, infection and low blood counts. Chemotherapy may also cause sexual side effects such as vaginal dryness, less interest in sexual intimacy and pain or discomfort during sex.

It may sound scary to think of being “on chemo” for a long time. But remember that chemotherapy affects different people in different ways. Some people have many side effects, while others have very few. The

important thing is to talk about all physical and emotional side effects with your healthcare team so they can help you have the best quality of life, no matter what treatment you are receiving.

There are many ways to help prevent and manage side effects. Don't wait until you feel discomfort! Talk with your doctor about side effects before you start treatment. Some side effects, like nausea, can be prevented altogether. Your doctors can give you medicine ahead of time and offer practical tips for managing side effects once they start.

Radiation Therapy

Radiation therapy is a **local therapy** that controls specific areas of cancer where it has spread. It focuses the power of high-energy x-rays on areas of your body that need to be treated. This may include your lymph nodes or other parts of your body. The radiation is thought to cause breaks in strands of DNA, which can keep the cancer cells from dividing.

In metastatic breast cancer, radiation is used to shrink tumors, to improve your quality of life and to lessen pain. Most often, it is used to manage pain from tumors in the bone, to treat or prevent symptoms in the brain or lungs, or to lessen pain and prevent injury to the nerves by treating tumors of the spine that are pushing on the spinal cord. It is unlikely that radiation will get rid of the cancer completely. But it may improve pain or symptoms from nerve damage, and in doing so improve your quality of life.

Radiation is most often given by **external beam**. From outside the body, a machine directs high-energy rays at the cancer. The doctor finds the exact areas to be treated after a physical exam and a review of your radiology tests. Next, you will lie on a flat table while

the doctor finds the areas to be treated. Small tattoos the size of freckles are placed on the skin to ensure the treatments are precise. The total dose of radiation and the number of treatments vary based on the size and location of the cancer, the reason for treatment, other treatments you are receiving and your overall health.

In some cases, radiation may be given from inside the body through **catheters** (thin plastic tubes that can be inserted into a body cavity) containing radioactive seeds.

Radiation therapy is usually painless. The side effects of radiation therapy are very specific to where you receive the treatment. If you receive radiation to the liver, for example, it's possible to have nausea or vomiting. In brain mets, radiation treatment can cause changes in thinking and memory. Talk with your radiation oncologist before and during treatment about side effects, so you know what to expect. Your providers can help you prepare.

Surgery

Surgery is rarely done for metastatic breast cancer, but if you have pain or bleeding, removing the **primary** (original) tumor may help ease symptoms.





Your Treatment Options as a Young Woman

As a young woman with metastatic disease you have different treatment options than a woman who has started menopause, because of the way your body makes hormones.

If you have hormone receptor–positive breast cancer, you may be able to take a SERM (see page 39). Your doctor also may recommend that you shut off your ovaries, either with surgery or with medicine (**ovarian ablation**, also called **ovarian suppression**). Shutting off the ovaries significantly lowers your body’s level of estrogen and may stop the cancer from growing.

Medicines that shut down ovaries work by turning off signals from your brain that regulate the function of your ovaries. They keep your ovaries from making and releasing estrogen. These medicines are called **luteinizing hormone-releasing hormone (LHRH) agonists** or **gonadotropin-releasing hormone (GnRH) agonists** (see page 41). They are given by injection every 1 to 3 months.

Ovarian ablation with medicine is gradual and happens over a period of weeks. Side effects may include hot flashes, mood changes, sexual concerns and other menopausal symptoms. The effects are not permanent, and ovarian function usually returns after treatment is stopped.

You may also consider having your ovaries removed with surgery. In an **oophorectomy**, the ovaries are removed through the vagina via a cut in the lower belly or a small cut at the top of the vagina using a **laparoscope** (a viewing tube to see the structures within the belly and pelvis). Removing the ovaries takes away most of the estrogen in your body. Your **adrenal glands** (glands over the kidneys that help control important body functions) will still produce small amounts of estrogen.

Removing your ovaries will significantly reduce your risk of the cancer growing, but it will cause you to go suddenly into menopause instead of having the slow transition that natural menopause permits. Side effects include hot flashes, an increased risk for heart disease, bone loss or fractures, and decreased sexual desire.

Taking part in a clinical trial can offer you access to new treatments that are not available outside a trial and may prove to work better than standard treatments. You will also help researchers develop better treatments for other young women. (Learn more on page 8.)

Treatment decisions are highly personal, and you should talk to your healthcare provider about your options. You might find it helpful to connect with other young women coping with metastatic breast cancer. We encourage you to contact our **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** or via online chat at **lbcc.org/helpline** for guidance, information and peer support. Our trained volunteers are here to listen and help you. Look on page 50 for a list of other resources to help you.

Choosing Your Treatment

Treatments for metastatic breast cancer may be given alone or in combination. You and your doctor will decide together based on where the cancer is located, how fast it grows and what factors make it grow.

Your doctor's recommendations will take into account your age, health and lifestyle. The goal is to control the cancer while minimizing side effects that impact your life. You may start with either a combination of medicines or a single medicine, to see whether it works well on its own. With more than one medicine, it can be hard to tell which one is working best, and it can be difficult to decide which one is causing side effects. Chemotherapy tends to have more difficult side effects than other treatments. Depending on the type of breast cancer you have, you may start with a treatment other than chemotherapy.

It is important for you to understand why your doctor recommends a specific treatment and why one treatment might benefit you more than another. Ask your doctor about how well each treatment works and how the side effects could impact your life. Your healthcare team may also know of clinical trials that could work for you. If they do not mention clinical trials, ask about them.

Choosing among many treatment options can feel overwhelming. Take time to learn about and discuss treatments with your healthcare team. Doing so will help you feel confident that you are making sound choices.

Paying for Treatment

Many or all of your treatments should be covered by private or government health insurance. It is critical that you or your doctor speak with your insurance company before you begin treatments.

If you have some insurance but it's not enough, or if you don't have insurance, talk to your doctor about your options. In a clinical trial, some of your costs may be covered. If you live far away from the treatment center, your facility might be able to help you find rides or pay for travel.

Many companies that make medicines have patient assistance programs and copay assistance programs to help pay for the medicines you need or the copays associated with them. Another copay resource is the Patient Access Network (PAN) Foundation. Its Metastatic Breast Cancer fund gives financial help for out-of-pocket costs for prescribed medical treatments. For more information, visit panapply.org or call (866) 316-7263.

Professionals in your treatment facility can help you find more financial resources, discuss disability options and solve problems; these people include social workers, patient navigators or advisors in the finance department.

LEARN MORE

To learn more, visit LBBC.ORG and read our *Guide to Understanding Financial Concerns*.



Treatments in the Pipeline

Herceptin. Femara. Xeloda. These medicines are now familiar, but it wasn't long ago that no one had heard of them. Treatment options evolve constantly, and new treatments and tests are being developed every day. Many treatments we now take for granted didn't exist just a few years ago.

Keeping Up to Date

How do you keep track of treatments under study that may benefit you? Many resources can help you find a clinical trial that will fit your treatment needs, disease type, treatment history and lifestyle.

Start by talking with your healthcare team about clinical trials that may be available to you at your cancer center or nearby. Many doctors take part in ongoing trials or know about others enrolling people all over the country. If your oncologist doesn't have an available trial for you, ask how you can learn about trials at other treatment centers. Many facilities have libraries for people with cancer, and a medical librarian or health educator can help you research clinical trials.

Other people may know about studies. At LBBC, we can connect you with women through our **Breast Cancer Helpline** toll-free at (888) 753-LBBC (5222) or via online chat at lbcc.org/helpline. This resource is staffed entirely by trained volunteers, many who took part in clinical trials themselves. You can also get information about open trials on LBBC.ORG. For a list of other helpful websites, see page 50.

What Happens Once Treatment Begins

As a person with metastatic breast cancer, tests will become a part of your life. These tests help you and your doctor figure out whether the treatment is keeping the cancer from growing or making it shrink. Tests also may show that the cancer is growing, despite treatment.

Testing can prevent you from suffering needlessly from the side effects of a treatment that isn't working. Your doctor can make sure your quality of life is preserved, and that side effects are lessened, by using only treatments that work.

No single test works for everyone or perfectly measures whether the cancer is progressing. Your doctor may use a variety of tests. Different tests are used for different types of metastasis and different areas of cancer. Your doctor may track your treatment over time to see whether it works and if the side effects are tolerable. Tests may include:

- Regular physical exams, to monitor the effects of treatment, assess side effects and decide if more tests should be done.
- Blood tumor marker tests**, which look at your blood for evidence cancer may be growing. Usually, one tumor marker test is not enough to give a complete picture. Sometimes markers go up, but an MRI or CT test shows the cancer has gotten smaller. If the tumor markers go up, ask about other tests to see if the cancer is progressing. Generally, doctors who use

these tests monitor trends in tumor markers, rather than accept a single increase as evidence a treatment has stopped working.

❖ **Chest x-rays**, to look for breast cancer in your lungs.

❖ **Nuclear bone scans**, to look for breast cancer in your bones. A small dose of a radioactive substance, injected into your vein, will reveal areas of new bone in an x-ray photograph.

❖ **MRI**, or **magnetic resonance imaging**, which uses radio waves and a powerful magnet linked to a computer to take detailed pictures inside your body. These pictures can show the difference between normal and diseased tissue. MRI makes better images of some organs and soft tissues than CT or x-ray. MRI is especially useful for looking at the brain, the spine, the soft tissue of joints and inside bones.

❖ **CAT (Computerized Axial Tomography) scans**, also called **CT scans**, to take three-dimensional x-ray pictures that give detailed images of your internal organs.

❖ **PET (Positron Emission Tomography) scans**, to help find the location of the cancer. They begin with an injection of sugar and a small amount of radioactive material. Because of the high amount of energy that breast cancer cells use, areas of cancer absorb large amounts of the radioactive sugar. After the sugar has traveled through your body, a special camera on the PET machine detects the radioactivity to help find the cancer's location.

Whether or not you believe they are significant, it is important to report any symptoms, side effects or changes since you began treatment. Write down how long you have had side effects and words to describe them, and rate your discomfort on a scale of 1 (not uncomfortable) to 10 (the most uncomfortable you have ever been). Be as specific as possible, and let your team know how much side effects impact your life.

Reporting side effects doesn't always mean the treatment will be stopped. Your doctor might change the dose or spread out treatments over a longer period. Or you and your doctor may talk about other medicines or lifestyle changes that could help lessen or stop the side effects. You will decide together whether continuing with a certain treatment is right for you.

If you have questions or doubts about tests or test results, ask questions or get a second opinion.



Managing Ongoing Treatment

In general, you will get a treatment until the treatment no longer works or the side effects become too severe.

Your doctor may from time to time offer you a “treatment break” for a special occasion or for travel. You could have other reasons for taking a break, like giving your body a few weeks of rest from side effects. Talk to your doctor about this option. Ask if you can return to the same treatment after the break or if you would need to start a different treatment.

Remember, cancer and treatments do not have to dictate your life choices. Talk with your team about treatment plans and options that will make it easier for you to do the things you love to do.



QUESTIONS TO ASK ABOUT QUALITY OF LIFE

As you begin a new treatment, consider not only your medical needs but also what makes life meaningful for you.

Consider:

- 1 What does “quality of life” mean to me? How do I define having a good life while living with metastatic breast cancer?
- 2 Do the benefits of the treatment outweigh its impact on my day-to-day life?
- 3 Will my treatments impact my goals and desires?
- 4 How might I and my healthcare team work together to enhance my quality of life?
- 5 What side effects worry me most?
- 6 Am I willing to take medicine or try a complementary therapy to offset side effects?
- 7 What level of discomfort, pain or fatigue am I willing to tolerate? Will taking medicine for pain impact my alertness or my ability to enjoy life? How can I find a good balance?
- 8 How helpful is my support system? How can I get the support I need?
- 9 What resources can help me explain my support needs to my loved ones?

Your healthcare team wants to find treatments that will not only control the cancer, but also allow you to enjoy your life. It is very important to realize that you do not have to stay on any treatment that makes you feel awful. If a treatment makes you uncomfortable or severely disrupts your daily life, your providers will work with you to help minimize side effects or find other options.



Moving Forward With Your Life

Treatment will likely become a regular part of your life. But by weighing its impact on your daily activities, you can take some control over how it affects you.

Talk to your healthcare team about your concerns — and your goals. Do you want to travel? Continue working? Spend more time with your friends, children or grandchildren? Try something you've never tried before?

Your team can help you figure out how to reach your goals while still taking care of your medical needs. If a treatment stops working, you will begin this process again, asking yourself and your doctor: What are my options and personal goals? What is the best treatment for me at this point in my life?

Because maintaining your energy is important, consider the things that you really enjoy or are most important to you in everyday life (cooking, playing with your children, working, etc.) and delegate the rest. Family, friends and members of your faith community usually are willing to help but don't always know what to do. Don't be afraid to ask for help. Your loved ones will not know what you need unless you ask.

Sign up for a website to help you delegate tasks (see page 53). Journal or blog about your experiences, needs or desires so everyone knows how you are doing and how they can best support you. These sites allow you to give updates without having to talk for hours about what is going on or repeat the same story many times.

When friends ask how they can help, you or someone close to you can send a link to your page. Appoint a “quarterback” from your support team to update your site, communicate with your email tree or make phone calls on your behalf. A partner or a trusted friend

might be the right person for this job. You could even make your own business cards with your Web link or your quarterback's telephone number.

These strategies can reduce stress and allow you to spend more time doing things you love rather than feeling the need to return phone calls after every appointment, treatment or scan.

Explore grocery delivery or meal-making services, or ask for gift certificates for these services. Cleaning services (or gift certificates for them) are another way to get help.

Because your needs may change over time, scheduling a regular night with friends or a periodic family talk can help you communicate with your loved ones and keep everyone on the same page. You may also benefit from a support group, an oncology social worker or another place where you can talk with those who understand.

At some point, you and your doctor may decide together to stop pursuing treatment. Perhaps there are no further therapies available that are known to be effective, or the side effects are outweighing the benefits.

Your doctor may recommend **palliative care**. Doctors and researchers define palliative care as specialized medical care focused on providing relief from the symptoms, pain and stress of serious illness. This includes considering your values, preferences and needs, as well as those of your family and loved ones. Palliative care providers treat the physical symptoms of illness, while also addressing sources of social, emotional and spiritual distress.

Your team provides palliative care at every stage of your treatment. But the term is often associated with the end of cancer treatment.

Hospice, a service that may be given at your home or at a medical facility, is a part of palliative care. Hospice includes palliative care but usually is added after you stop active cancer treatment. In a hospice setting, your team focuses on the quality rather than the quantity of your life.

Starting hospice does not mean your doctors have given up on you. Your doctors will instead emphasize care that maintains or raises your quality of life in the short-term. Choosing hospice does not mean you are giving up control of your care. At any point you and your healthcare team may decide together to start treatment again. Whatever you decide, your medical team will continue to care for you.

If you want to learn more about these services but your team does not mention them, do not be afraid to bring them up. Exploring these services before you need them will help you think about your desires and communicate them to the people you love.

LEARN MORE

For more information, visit LBBC.ORG and read *Metastatic Breast Cancer Series: Understanding Palliative Care*.

Your feelings may change over the course of your treatment and if you need to switch or stop treatments, you could feel a variety of emotions. We're always here for you, through our **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** or via online chat at lbbsc.org/helpline.

About Specific Treatments

Here, we go into more details about some of the therapies you may receive during treatment for metastatic breast cancer.

Common Hormonal Therapies

SERMS

SERMs, or **selective estrogen receptor modulators**, work by blocking the effects of estrogen on cancer cells so the estrogen cannot stimulate the cancer to grow.

Two of these medicines are:

● **Tamoxifen**

● **Toremifene citrate** (Fareston)

SERMs are daily pills and work against estrogen receptor-positive metastatic breast cancers in pre- or postmenopausal women.

Tamoxifen keeps the estrogen in your body from “communicating” with estrogen receptors on the cancer cells. Your cells will no longer “see” the estrogen and will stop growing.

Common side effects include hot flashes and vaginal discharge, dryness or irritation. If you have spotting between periods, start having periods after having stopped or have other changes in vaginal bleeding, you should see your gynecologist. Call your provider right away or go to the emergency room if you develop pain, redness or swelling in your lower leg (calf), shortness of breath, chest pain, sudden severe headache,

confusion or trouble speaking or moving. Tamoxifen has some rare serious side effects, including an increased risk of blood clots and endometrial (uterine) cancer.

Toremifene citrate, which is closely related to tamoxifen, is used in postmenopausal women with hormone-sensitive metastatic breast cancer or with an unknown receptor status. It is an alternative to tamoxifen. Studies show it works as well as tamoxifen and has similar side effects.

AROMATASE INHIBITORS

These daily pills block the activity of the enzyme aromatase, which makes small amounts of estrogen in postmenopausal women. **Aromatase inhibitors** may be given as the first treatment for metastatic breast cancer or after tamoxifen or other hormonal treatments stop working.

The names of these medicines are:

- **Anastrozole** (Arimidex)
- **Letrozole** (Femara)
- **Exemestane** (Aromasin)

Aromatase inhibitors work only when the ovaries no longer produce estrogen, either because of menopause, surgical removal of the ovaries or medicines that shut down the ovaries. If your ovaries still work, these medicines cannot stop them from making estrogen.

Aromatase inhibitors increase the risk for bone thinning, osteoporosis and bone fractures, but these are rarely problems in metastatic disease. Your doctor will monitor you and may recommend bone-strengthening medicine, if needed. Other side effects include hot flashes, night sweats and bone, joint and muscle aches or stiffness.

ERAS

ERAs, or **estrogen receptor antagonists**, are a family of hormonal therapy, approved only for use in metastatic disease. They stop the activity of estrogen

on cancer cells, keeping the cancer from growing. These medicines are used when the cancer no longer responds to other hormonal therapies.

One common ERA is:

- **Fulvestrant** (Faslodex)

For the first month, fulvestrant is given as two injections every 2 weeks. Afterward, it is given as two injections every 4 weeks. Hot flashes, mild nausea and fatigue are the major side effects. Before starting on fulvestrant, tell your doctor if you have liver problems, bleed easily or take blood thinners.

MEGESTROL ACETATE (MEGACE)

Megestrol acetate is a man-made form of the hormone progesterone that counteracts some of the effects of estrogen. It is used when the cancer stops responding to other hormonal therapies.

Megestrol acetate, as a pill or liquid, is usually taken once a day. It can also be prescribed in smaller doses to be taken at regular times during the day. One side effect is weight gain, so your doctor may prescribe megestrol acetate if you have loss of appetite and weight loss.

LUTEINIZING HORMONE-RELEASING HORMONE (LHRH) AGONISTS

Also called gonadotropin-releasing hormone (GnRH) agonists, these medicines stop the ovaries from making estrogen, which may stop the cancer from growing. They are given by injection every 1 to 3 months.

The names of these medicines are:

- **Goserelin** (Zoladex)
- **Leuprolide** (Lupron)
- **Triptorelin** (Trelstar)

Side effects may include hot flashes, mood changes, sexual concerns and other menopausal symptoms.



Common Targeted Therapies

TRASTUZUMAB (HERCEPTIN)

Trastuzumab, the most common medicine for HER2-positive breast cancer, attacks the HER2 protein on the outside of a cell. It blocks the growth of cancer cells or sends a signal to the immune system to destroy them.

Trastuzumab is given by infusion weekly or every 3 weeks. It has very few side effects, but several studies have shown a small but significant risk of heart problems. Let your doctor know about any history of heart difficulties. Your heart function will be monitored before, during and after treatment.

PERTUZUMAB (PERJETA)

Pertuzumab is used to treat HER2-positive breast cancer, and works similarly to trastuzumab. It is given by infusion every 3 weeks. Pertuzumab has very few side effects, but as with trastuzumab, let your doctor know about any history of heart problems.

T-DM1 (KADCYLA)

T-DM1, also called ado-trastuzumab emtansine, combines trastuzumab with chemotherapy. It is able to send the chemotherapy medicine straight to the HER2-positive cancer cells. T-DM1 is given by infusion every 3 weeks. It has fewer side effects than traditional chemotherapy. Since it contains trastuzumab, let your doctor know about any history of heart difficulties before you start taking T-DM1.

LAPATINIB (TYKERB)

Lapatinib is a medicine in the dual tyrosine kinase inhibitor family. Like trastuzumab, lapatinib blocks the action of the HER2 protein. But while trastuzumab works on the outside of the cell, lapatinib works on the inside. Because of this difference, lapatinib works in some HER2-positive cancers that no longer respond to trastuzumab.

A daily pill, lapatinib is given in combination with capecitabine or letrozole (for HER2-positive, hormone-sensitive metastatic breast cancers). Common side effects include rash, fatigue and diarrhea. Before starting lapatinib, talk to your doctor about any heart and liver problems.

EVEROLIMUS (AFINITOR)

Everolimus stops cancer cells from dividing and may block the growth of new blood vessels that tumors need to grow. It also decreases the body's immune responses. It is FDA-approved to be used along with exemestane for postmenopausal women with hormone receptor-positive metastatic breast cancer. It is also being studied in HER2-positive metastatic breast cancer. Everolimus is given as a pill. It can have rare but serious side effects and often causes mouth sores, change in taste, rash and diarrhea.

PALBOCICLIB (IBRANCE)

Palbociclib is a CDK 4/6 inhibitor, a new family of medicines that stop certain proteins from sending signals to cells that tell them to grow and divide. Palbociclib is a pill that can extend the time of disease control when given with standard hormonal therapies.

It is FDA approved to treat hormone receptor-positive, HER2-negative metastatic breast cancer when given with:

- **letrozole**, as the first hormonal therapy treatment after a diagnosis of metastatic breast cancer for women who have gone through menopause.
- **fulvestrant**, when the metastatic breast cancer grows after other hormonal therapy, no matter what the menopausal status is.

Palbociclib can cause low blood counts. Your doctor will monitor your blood counts while you take this medicine and may adjust your dose.

Many forms of targeted therapy are being developed and tested in clinical trials, so this list is expected to grow.



Common Chemotherapy Treatments

ANTHRACYCLINES

Anthracyclines kill cancer cells by stopping cell growth. They are given by vein weekly or every 2 to 4 weeks, either alone or in combination with other medicines.

Three anthracyclines used in metastatic breast cancer are:

- **Doxorubicin** (Adriamycin)
- **Epirubicin** (Ellence)
- **Liposomal doxorubicin** (Doxil)

Side effects include nausea, vomiting, hair loss, low blood counts, risk for infection and mouth sores. Liposomal doxorubicin injections also could cause redness, pain and swelling of the hands and feet.

You may not be able to take anthracyclines if you have a history of heart problems. Anthracyclines increase the risk of **congestive heart failure**, when the heart can't pump enough blood to the body's other organs. Your heart function will be tested before and throughout treatment. If your risk for heart problems becomes too high, your doctor will switch you to a different treatment or give you an extra medicine known to protect the heart.

TAXANES

Taxanes can prevent tumor growth by stopping cell division.

Three taxanes given for metastatic disease are:

- **Docetaxel** (Taxotere)
- **Paclitaxel** (Taxol)
- **Nab-paclitaxel** (Abraxane)

Docetaxel and paclitaxel are given intravenously either weekly or every 3 weeks. Side effects of docetaxel include low blood counts, risk for infection, fatigue,

hair loss, fluid retention, nail and skin changes and loss of natural tears. Both medicines carry a risk of allergic reaction during infusion and can cause joint pain, flu-like symptoms and **neuropathy**, nerve damage in the hands and feet.

Nab-paclitaxel is paclitaxel wrapped in the protein albumin, which allows it to be given in water instead of a special solution. By avoiding the solution, you may not need to take steroids or other medicines before treatment like you would with regular paclitaxel. Nab-paclitaxel is given in less than 30 minutes compared to up to 3 hours for regular paclitaxel. Side effects are generally similar to those of regular paclitaxel, but nab-paclitaxel has a smaller risk of allergic reaction.

Taxanes may be given alone or in combination with other treatments, like trastuzumab (see page 42).

PLATINUM-BASED CHEMOTHERAPIES

Platinum-based chemotherapies, given by vein, interfere with the action of DNA inside cancer cells.

Some platinum-based medicines are:

- **Cisplatin** (Platinol)
- **Carboplatin** (Paraplatin)

Side effects include low blood counts, hair loss, loss of appetite or weight, diarrhea, nausea and vomiting, and numbness or tingling in the fingertips and toes. Rare side effects include kidney problems and hearing loss.

Other Chemotherapy Medicines

CAPECITABINE (XELODA)

Capecitabine, given alone or with docetaxel or paclitaxel, is effective against some cancers that stop responding to anthracyclines or taxanes. It may also be given with lapatinib (see page 43) for HER2-positive cancers.

Capecitabine is given as a pill 2 times per day for 7 to 14 days followed by 1 week off, but your dose and schedule can be changed. It is common for the dosage to be adjusted at the beginning of treatment, because people absorb and process capecitabine differently.

Side effects may include mild nausea, **hand-and-foot syndrome** (redness, pain and swelling in the hands and feet), diarrhea and mouth sores. Capecitabine usually does not cause hair loss. If you have pain or diarrhea, talk to your doctor right away. You may be able to take a lower dose that makes you more comfortable while maintaining treatment effectiveness.

ERIBULIN (HALAVEN)

Eribulin stops cancer cells from dividing. It is FDA-approved for people who have taken an anthracycline and a taxane in the past, for either early-stage or metastatic disease, and have received at least two chemotherapy regimens for metastatic disease. It is given by vein, usually once a week for 2 weeks, followed by 1 week off. Side effects may include constipation, fatigue, fever, low blood counts, hair loss, menopausal symptoms, neuropathy, nausea and weakness.

GEMCITABINE (GEMZAR)

Gemcitabine works by depriving cancer cells of the nutrition they need to grow. Gemcitabine, given with paclitaxel, carboplatin, or on its own, is FDA approved for use when an anthracycline stops working or you cannot take it for other reasons.

Usually, gemcitabine is given by vein 3 weeks in a row, followed by a 1-week rest period, but dose schedules vary. Common side effects include mild to moderate nausea and vomiting, fatigue, diarrhea, skin rash and low blood counts. If you have kidney or liver disease or are receiving radiation treatment, you may not be able to take gemcitabine.

IXABEPILONE (IXEMPRA)

Ixabepilone stops the growth of tumor cells by targeting a protein that helps cells multiply. It is approved for use when other chemotherapy medicines do not work against the cancer or when the cancer stops responding to treatment.

Ixabepilone is given intravenously, either alone or with capecitabine, once every 3 weeks. Treatment usually takes about 3 hours. Because ixabepilone can cause allergic reactions, right before treatment you will be given steroid medicines to prevent them.

Common side effects include neuropathy; **neutropenia**, low white blood cell count, which carries a risk of infection; and allergic reactions such as itching, rash or breathing troubles. Other side effects include constipation, nausea, vomiting, muscle pain, joint pain, fatigue and general weakness.

VINORELBINE (NAVELBINE)

Vinorelbine stops cancer cells from dividing. It is given by infusion once a week for 6 to 10 minutes and may be used alone or in combination with other chemotherapy medicines.

Vinorelbine rarely causes hair loss. Common side effects are low blood counts, nausea or vomiting, muscle weakness and constipation.



Resources

Information is current as of March 2016 but may change.

Organizations That Can Help

CLINICAL TRIALS

- BreastCancerTrials.org
- cancer.gov/clinicaltrials
- cancertrialshelp.org
- CenterWatch.com
- ClinicalTrials.gov
- ecancertrials.com
- EmergingMed.com
- lbbc.org/metastatic-trial-search

INFORMATION AND SUPPORT FOCUSING ON METASTATIC BREAST CANCER

- AdvancedBreastCancerCommunity.org
- BCmets.org
- BrainMetsBC.org
- Living Beyond Breast Cancer: **Breast Cancer Helpline:** (888) 753-LBBC (5222), lbbc.org/helpline, lbbc.org/mets
- MetaCancer Foundation: metacancer.org
- Metastatic Breast Cancer Network: (888) 500-0370, mbcn.org
- METAvivor: (410) 263-3340, metavivor.org
- Patient Access Network Foundation (PAN)'s Metastatic Breast Cancer Fund: (866) 316-7263, panfoundation.org

INFORMATION AND SUPPORT WITH RESOURCES ABOUT METASTATIC BREAST CANCER

- ▮ Abramson Cancer Center of the University of Pennsylvania: OncoLink.org
- ▮ American Cancer Society: (800) 227-2345, cancer.org
- ▮ Association of Cancer Online Resources: acor.org
- ▮ Breastcancer.org
- ▮ CancerCare: (800) 813-4673, cancercare.org
- ▮ Cancer Support Community: (888) 793-9355, cancersupportcommunity.org
- ▮ Patient Advocate Foundation: (800) 532-5274, patientadvocate.org
- ▮ SHARE: (866) 891-2392, sharecancersupport.org
- ▮ Susan G. Komen: (877) 465-6636, komen.org
- ▮ Triple Negative Breast Cancer Foundation: Helpline: (877) 880-8622, tnbcfoundation.org

YOUNG WOMEN

- ▮ **LIVESTRONG**: livestrong.org/we-can-help/young-adults
- ▮ Sharsheret: (866) 474-2774, sharsheret.org
- ▮ Stupid Cancer: stupidcancer.org
- ▮ Young Adult Cancer Canada: (877) 571-7325, youngadultcancer.ca
- ▮ Young Survival Coalition: (877) 972-1011, youngsurvival.org

PLANNING AND CAREGIVING SUPPORT

- ▮ Caregiver Action Network: (202) 454-3970, caregiveraction.org
- ▮ CarePages.com
- ▮ CaringBridge: CaringBridge.org
- ▮ Lotsa Helping Hands: lbbc.lotsahelpinghands.com



Words to Know

Adrenal glands. Glands over the kidneys that help control important body functions. They produce small amounts of estrogen.

Anthracyclines. Chemotherapy medicines that kill cancer cells by stopping cell growth.

Aromatase inhibitors. Hormonal therapy medicines that block the activity of the enzyme aromatase, which makes small amount of estrogen in postmenopausal women.

Biopsy. Taking a small amount of tissue from the breast and looking at it under a microscope.

Blood tumor marker tests. Tests that look at your blood for evidence cancer may be growing.

Catheters. Thin plastic tubes that can be inserted into a body cavity.

Chemotherapy. Medicines that kill rapidly dividing cells, including those found in some breast cancers.

Chest x-rays. Tests that take a picture of the lungs, heart, airways, blood vessels and bones in the chest and upper back.

Clinical trial. A research study that tests how well new medical approaches work in people.

Combination therapy. Multiple medicines given together.

Compassionate use trial. A rare type of clinical trial that may provide people access to medicines already shown to be active and very close to FDA approval. Also called an expanded access trial.

Computerized Axial Tomography (CAT/CT) scans.

Tests that take three-dimensional x-ray pictures to give detailed images of your internal organs.

Congestive heart failure. A condition in which the heart can't pump enough blood to the body's other organs.

Doubled-blinded. A trial in which neither you nor your doctor knows what treatment you are getting.

Early-stage. Breast cancer that is contained within the breast or nearby lymph nodes (stage 0 through stage II).

ERAs (estrogen receptor antagonists). Hormonal therapy medicines approved only for use in metastatic hormone receptor-positive disease. They stop the activity of estrogen on cancer cells, keeping the cancer from growing.

External beam. How radiation therapy is most often given. A machine directs high-energy rays from outside your body at the cancer.

Gonadotropin-releasing hormone (GnRH) agonists. Medicines that stop the ovaries from producing and releasing estrogen. Also called luteinizing hormone-releasing hormone (LHRH) agonists.

Hand-and-foot syndrome. Redness, pain and swelling in the hands and feet.

HER2-positive breast cancer. Breast cancer that grows because of too many human epidermal growth factor receptor 2 (HER2) proteins on breast cells.

Hormonal therapies. Treatments that block or remove hormones to lower the risk of cancer returning in hormone receptor-positive breast cancer.

Hormone receptor-positive breast cancer. Disease that shows presence of hormone receptors for estrogen (ER+) or progesterone (PR+), or both.

Hospice. A program that provides special care for people who are near the end of life, and for their families, either at home, in special facilities or within hospitals.

Institutional Review Board. A committee made up of doctors, nurses and lay people who review and approve studies involving humans. Federal rules require all clinical trials to go through an Institutional Review Board.

Intravenously. Given by vein.

Laparoscope. A viewing tube that may be used to see the structures within the belly and pelvis during surgery to remove the ovaries.

Luteinizing hormone-releasing hormone (LHRH) agonists. Medicines that stop the ovaries from producing and releasing estrogen. Also called gonadotropin-releasing hormone (GnRH) agonists.

Local therapy. Treatment that kills the cancer in specific places where it started, or has spread. Examples are surgery and radiation therapy.

Locally advanced. Breast cancer that has traveled from the breast to nearby tissue such as the skin or chest wall (stage III).

Magnetic resonance imaging (MRI). An imaging test that uses magnet and radio waves to create cross-sectional images of specific areas of the body.

Metastatic (stage IV). Breast cancer that has traveled away from the breast and nearby lymph nodes to tissues or organs far from the breast, such as the bones, lungs, liver or brain.

Neuropathy. Nerve damage in the hands and feet.

Neutropenia. Low white blood cell count. It can make infection more likely.

Non-blinded. A trial in which both you and your doctor know what treatment you are receiving. Also called an open-label study.

Nuclear bone scans. Tests that look for breast cancer in your bones.

Oophorectomy. Surgery to remove the ovaries.

Orally. When medicine is taken by mouth, in pill or capsule form.

Ovarian ablation/suppression. Surgery, radiation therapy, or medicines used to stop the ovaries from working.

Palliative care. Things that ensure you are living in a way that enhances your everyday activities, such as complementary practices to center you or strengthen your body, pain management medicines, and emotional, physical, social and spiritual support.

PARP inhibitors. Targeted medicines that work by preventing cancer cells from fixing their own DNA. This helps chemotherapy treatments work better. They have been approved in other diseases but not yet in breast cancer.

Positron emission tomography (PET) scans. Tests that use a small amount of radioactive sugar, injected into a vein, and a scanner to make detailed, computerized pictures of areas inside the body. The pictures can be used to find cancer cells in the body.

Phases. Steps that new treatments must go through before they can become standard treatments.

Phase I. Trials that test a new treatment in humans for the first time. The purpose is to make sure a treatment is safe.

Phase II. Trials that continue to test the safety of a treatment and begin to decide if it has an effect on the cancer.

Phase III. Trials that compare a promising new treatment (or new way of using an existing treatment) to the current standard treatment.

Phase IV. Trials sometimes done after a new treatment has been approved the FDA. These trials gather more information about the risks, benefits and side effects of a new treatment and continue to evaluate how well it works.

Placebo. An inactive substance that you may receive during a clinical trial.

Port. Small device put under the skin with surgery that gives doctors easy access to veins to take blood or give medicine. Also called mediport or port-a-cath.

Primary tumor. The original tumor.

Radiation therapy. A treatment that uses the power of high-energy radiation from x-rays to damage cancer cells in specific areas of the body.

Randomized clinical trial. A trial in which people are assigned by chance to separate study groups that compare different treatments. These trials are considered the most reliable form of scientific evidence.

SERMs (selective estrogen receptor modulators). Hormonal therapy medicines that work by blocking the effects of estrogen on hormone receptor-positive breast cancer cells so the estrogen cannot cause the cancer to grow.

Single-agent therapy. One medicine given at a time.

Single-blinded. A trial in which you don't know what treatment you are receiving, but your doctor knows.

Systemic therapy. Treatment that kills cancer throughout the body. Examples are chemotherapy and targeted therapy.

Targeted therapy. Medicines used when a specific feature or marker is present on or within a cancer cell. Only cancers with that feature or marker are expected to respond to the therapy.

Taxanes. Chemotherapy medicines that can prevent tumor growth by stopping cell division.



Many thanks to the individuals who gave their time and expertise for this guide:

AUTHORS

Anna Shaffer

Janine E. Guglielmino, MA

LIVING BEYOND BREAST CANCER REVIEWERS

Amy Grillo

Jean A. Sachs, MSS, MLSP

LEAD MEDICAL EDITOR

Medical Oncology

Clifford A. Hudis, MD

Memorial Sloan Kettering Cancer Center

New York, New York

MEDICAL ADVISORY COMMITTEE REVIEWERS

Advocacy

Lisa D. Black

Bryn Mawr, Pennsylvania

Elyse Spatz Caplan, MA

Morristown, New Jersey

Surgical Oncology

Karen J. Hendershott, MD

Swedish Hospital, Seattle, Washington

Oncology Nursing

Evelyn Robles Rodriguez, RN, MSN, APN, AOCN

MD Anderson Cancer Center at Cooper

Camden, New Jersey

Oncology Social Work

Sage Bolte, PhD, LCSW, CST, OSW-C

Life with Cancer

Inova Dwight and Martha Schar Cancer Institute

Fairfax, Virginia

Radiation Oncology

Jennifer R. Bellon, MD

Dana-Farber Cancer Institute/Brigham and

Women's Hospital and Harvard Medical School

Boston, Massachusetts

MANY THANKS TO THE CONTRIBUTORS TO OUR FIRST EDITION:

Nancy U. Lin, MD

Dana-Farber Cancer Institute

Page Tolbert, MSW

Memorial Sloan Kettering Cancer Center

Carolyn Weaver, RN, MSN, AOCN

Fox Chase Cancer Center

CREATIVE DEVELOPMENT

Masters Group Design

BECK Photography

More Resources

Visit LBBC.ORG or call (855) 807-6386 to order our other *Metastatic Breast Cancer Series* publications:

- ☐ **Guide for the Newly Diagnosed**
 - ☐ Managing Stress and Anxiety
 - ☐ Understanding Palliative Care
 - ☐ Understanding Symptoms and Treatment Side Effects
-

Guides in our *Understanding Series*:

- ☐ **Guide for the Newly Diagnosed**
 - ☐ Clinical Trials
 - ☐ Complementary Therapies
 - ☐ Fear of Recurrence
 - ☐ Financial Concerns
 - ☐ Genetics and Family Risk
 - ☐ HER2-Positive Breast Cancer
 - ☐ Hormonal Therapy
 - ☐ Intimacy and Sexuality
 - ☐ Lymphedema
 - ☐ Treatment Decisions
 - ☐ Triple-Negative Breast Cancer
 - ☐ Yoga & Breast Cancer
 - ☐ Your Emotions
-

Guides in our *Breast Cancer InFocus Series*:

- ☐ Breast Cancer During Pregnancy
- ☐ Breast Cancer in Men
- ☐ Getting the Care You Need as a Lesbian, Gay or Bisexual Person



With you, for you.

This brochure is designed for educational and informational purposes only, as a resource to individuals affected by metastatic breast cancer. The information given is general in nature. For answers to specific healthcare questions and concerns, you should consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to be a substitute for professional medical advice or counseling.

© 2008, 2010, 2016 Living Beyond Breast Cancer, 3rd Edition.





**LIVING BEYOND
BREAST CANCER™**

With you, for you.

(855) 807-6386 • [LBBC.ORG](https://www.LBBC.ORG)

Funding and support provided by:

